

This book is funded by the Texas Health and Human Services Commission.

It is dedicated to all the mothers who shared their struggles with substance use and their dreams of living a happy life with their child(ren) to help others.



Introduction



he stories shared in this book reflect the experiences of 127 women who have been personally affected by addiction and 27 of their family members and significant others.

They generously shared their lives and stories with the author and her team through individual interviews and focus groups over an eight-year period from 2010 to 2018.

To truly understand the complex nature of addiction among women, we gathered stories from locations throughout Texas, including large metropolitan areas, remote rural communities, and coastal and border towns. All interviews and focus groups were audio-recorded and transcribed word-for-word to ensure we truly captured the voices and stories of the women and their significant others.



Chapter 1



y name is Hannah and I was a heroin user. I call heroin the mind, body and soul drug. It takes over your mind and soul to the point that you can't even rationalize your way to

recovery. My husband just couldn't understand how I could keep using. I love my kids. I kept saying that I loved my kids. I love my husband. I love my family. Why couldn't I stop for them? I don't understand it either. Your thinking is so sick when you're in your addiction. Like, I would tell myself it made me a better mom because it calmed my nerves, you know? Or, I thought it gave me energy. This disease will lie to you — you're powerless and hopeless. It completely takes over your body as well. The withdrawal symptoms are unbearable. You may be 15 years old but feel like you're 85. I mean, it's horrible and you want to die when you don't have the drug. It's a must-get. You have to have it. It's work to stay high. You just have to chase it, chase it, chase it. I didn't even want anything to do with my own baby. It was awful! I was more of a mother to the heroin. My baby would be crying and I'd just say, 'The baby's crying. Somebody go get the baby.' Meanwhile, I'm going into the bathroom to shoot up.



ccording to the American Society of Addiction Medicine, addiction is a treatable, chronic, medical condition that involves the brain, biology, environment and life experiences.¹

Those with addiction use substances or engage in behaviors that become compulsive and often continue to use despite harm to themselves or others.

There are normally four components to addiction:

- The loss of control over use.
- Social impairment.
- Risky use.
- Physical indicators.

The loss of control over use is after a person can no longer cut back or stop without assistance. Social impairment happens when more time, money and energy is put into substance seeking, use and recovery. Risky use is when use can harm oneself or others. The physical indicators are often when a person's tolerance increases to the use of the substance, so more is needed for the desired effect.

Withdrawal is another physical indicator that happens if the substance is suddenly discontinued. Because of withdrawal, it is possible for a person to be physically dependent on a substance but not technically meet the criteria for a diagnosis of addiction. For example, people can become physically dependent on opioid pain medications for pain management yet not meet the diagnostic criteria for addiction because they do not experience the psychological symptoms that can accompany addiction.

Addiction does not discriminate based on sex, ethnicity, educational level or socioeconomic status, making many people vulnerable to this chronic condition. If left untreated, addiction can seriously affect a person's quality of life and can lead to early death. Addiction prevention and treatment efforts are generally as successful as those observed with other chronic diseases such as diabetes, obesity and hypertension.

Women and Addiction

Millions of women in the United States have an addiction, which will be referred to as substance use disorders (SUDs) in the following pages. An estimated 19.5 million (15.4 percent) women 18 and older used an illicit substance in 2019, and 8.4 million (6.6 percent) women misused prescription medications.²

However, there are important differences between men and women when it comes to SUDs:

- SUDs progress more rapidly in women.
- Women are more likely to experience strong cravings when attempting recovery.
- Women are more likely to return to substance use. 3, 12, 13

While men and women experience SUDs, recovery for women is also associated with multiple challenges not necessarily experienced by men. Most notably, the stigma and judgment experienced by pregnant and parenting women with SUDs are barriers to accessing needed services. Additionally, 70 percent of women with SUDs have young, dependent children, yet few treatment facilities and recovery homes offer beds for women and their children across the United States.

Therefore, if women need residential treatment, they are often faced with separation from their children, a significant barrier to accessing care. One woman we interviewed offered her insight on the matter:

We're just treated differently than men. I think that's especially true if you have kids. If you have kids and you are a woman with an addiction — everything is different — from the way you're treated to the way you're looked at. If a man is addicted, he's on his own...he only has to care for himself. But if you have kids, people immediately think of you as not caring for your kids right, and that's not necessarily true. Lots of things go through a person's mind when they hear a mom is addicted to drugs or is on methadone or some other drug. It's just different. It's totally different for women.

Substance Use Disorders in Pregnant and Parenting Women

Pregnancy and parenting create unique challenges for women who are experiencing SUDs. In the United States, there has been a dramatice increase in the use of opioids in the pregnant population.^{4,5} Over the past two decades, the number of pregnant women with opioid use disorder (OUD) has quadrupled.^{5,6} According to the Centers for Disease Control and Prevention, as many as a third of pregnant women are prescribed an opioid during their pregnancy.⁴

Opioid use during pregnancy can lead to preterm birth, low birth weight, and Neonatal Abstinence Syndrome (NAS). NAS is a group of withdrawal symptoms observed in infants prenatally exposed to opioids.

Opioid Overdose and Maternal Mortality

One of the greatest risk factors for opioid use is death by overdose because of relapse into use.⁶ This is more evident following a period of reduced or no use when opioid tolerance has decreased, which can result in death. Under these circumstances, people might not realize their tolerance has decreased, then use the same amount of opioid previously used and experience an overdose.⁷ One woman whose daughter died because of overdose described the details of her daughter's death:

She would do heroin, but she wasn't hooked on it. That one time she just... I don't know what happened or how much she drew up, but she injected it all. She didn't wake up. Left two kids behind at home. But it was everything that was going on in her life, you know? She was just fed up with the world.

Opioids are currently the main driver of overdose deaths in the United States and were involved in 47,600 overdose deaths in 2017 (67.8 percent of all drug overdose deaths).8 Overdose deaths caused by prescription opioids have increased almost 600 percent among women in the United States, compared to 312 percent among men. Opioid-related deaths among pregnant women and new mothers has also climbed.9,10

The CDC defines pregnancy-related mortality as a death happening during pregnancy or the year that follows. Between 2007 and 2016, pregnancy-related mortality caused by overdose from all substances more than doubled in the United States. In 2016, overdose was identified as the leading cause of pregnancy-related mortality in Texas with prescription and illicit opioids

Summary

During our eight years of data research, we discovered the women who shared their stories with us are not victims — they are survivors. Their strength, perseverance and love for their children is what led them to eventually find peace and recovery. You might also come to understand the personal factors (mental health, trauma) and the social determinants (poverty, homelessness) and their role in substance use disorders. These women can be your sisters, daughters, mothers, friends, neighbors and co-workers.

Chapter 1

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Chapter 2



y name is Alice. I was the first person in my family to graduate from high school. My mother was a heroin addict, so we moved around a lot; constantly getting

evicted and finally ending up living in the projects.

My stepfather was very abusive to my mother. He used weapons to beat her every day and forced her into prostitution to support their heroin habit. My entire family used drugs. I witnessed brutal attacks. My mother stabbed her own sister multiple times while under the influence.

She also overdosed right in front of me. I remember always writing down the numbers on the license plates when she would get picked up for dates just in case she didn't make it back. Her sister was murdered that way. My stepfather sexually and physically abused us. My first memory in life is sitting near a Christmas tree on his lap while he was sexually abusing me. Holidays are a real challenge for me now. This abuse went on until I was 12 years old.



he women's descriptions of how their substance use began is consistent with the research and present recurring themes throughout this chapter. Nationally, 50-90 percent of people who seek treatment for

an SUD have experienced one or more traumatic life experiences such as: childhood trauma, intimate partner violence, mental illness, loss and unresolved grief, and environmental stressors.¹

Childhood Trauma

The women we interviewed described recurring, unaddressed childhood trauma, coupled with mental illness and unsupportive environments that lacked needed physical and emotional resources. ^{6, 7, 9} Childhood trauma is closely related to SUDs in women and the severity of that trauma can predict more frequent relapse, multiple treatment admissions and a delayed recovery process. Their stories describe how they used substances to cope with hard situations.

I started using when I was 12 years old. My mom's an alcoholic. My father walked out on her when I was 2 weeks old. Her boyfriends molested me, did things to me. So, I turned to drugs. When I was about 30, I tried taking methadone, but I'd always relapse and go back to heroin. I guess it was because I really wasn't ready to quit.

Many described how childhood trauma affected their current quality of life and negatively impacted their mental health. Yet for some of the women, it often took

time for them to make the connection between their prior trauma, mental health and substance use.

Had I known all along that (post-traumatic stress disorder) and severe depression had been my problem my whole life, I don't think I would have automatically turned to drugs to make myself feel better; to make myself feel normal, you know? I started popping a lot of pills... Xanax, Percocets, anything just to feel normal.

Intimate Partner Violence

The women also described the trauma they experienced following violence involving their intimate partners. Nationally, substance use is involved in 40-60 percent of all incidences of intimate partner violence (IPV) and having experienced IPV is considered a predictor of SUD development in women. The Many women in these abusive relationships report being coerced by their partners to use substances. Women who experience IPV are more likely to continue substance use through their pregnancies. The women we interviewed reported substance use provided them with a safe, "loving place" away from reality. One woman shared how she used substances to "escape the pain" in her relationship:

Anyone who has an addiction, a stress overload, that is our escape. That stress is gonna push us to get high. The drug is a welcoming, loving place. So, if I'm pregnant and my boyfriend is beating me, I'm gonna go get high to escape that pain.

The women also described using substances to "comfort" and "numb" themselves from emotional pain:

We don't know how to cope with reality, and so we're scared of it. When we relapse... just to go back to the comfort of numbing it all, you know. That's one of my things. I'm scared of reality. I'm actually used to numbing it whether it's methadone or something else. That's one of the things I pray for... give me the strength to cope with this reality.

Mental Illness

People with SUDs often experience mental illness. Depression, post-traumatic stress disorder (PTSD), and anxiety happen in up to 70 percent of pregnant women with SUDs. 4, 8, 9 The overlap between SUDs and serious mental illness (SMI), such as schizophrenia and bipolar disorder, is also well supported by evidence. One in four people with SMI has a co-occurring SUD. 10, 12, 16 One woman explained how her childhood trauma, undiagnosed mental illness and her son's death affected her ability to cope and led her toward substance use:

I think my troubles stemmed from being raped as a child and then when my son died — it just destroyed me. I also think that if I would have been diagnosed with bipolar at an earlier age, it might have prevented all of this from happening to me.

Another woman described how her pregnancy and her troubled relationship with her partner resulted in her depression. She used heroin to help manage some of the uncontrollable symptoms she was experiencing:

I began to get really depressed when I was pregnant — dealing with our relationship problems.

I didn't want to be pregnant, and I was just getting depressed, and that's why I used. I was constantly fighting with (my baby's father) and going through stuff with him. He was still using, and I was having to stay clean, you know, because I was pregnant. So that caused even more turmoil and conflict.

Loss and Unresolved Grief

The relationship between loss, unresolved grief and SUDs appears to be important but is not yet fully understood. Grief following a loss can contribute to substance use and result in an SUD. Unresolved grief can happen when a person feels guilt over the loss, considers the loss to be unfair, or lost a loved one because of an unexpected or violent death.^{10, 11}

Feeling as though the loss has not been acknowledged, such as in the case of childhood sexual abuse, can also contribute to unresolved grief. This is particularly true when a person is living in an environment that lacks emotional support or fails to recognize the traumatic event that caused the loss and resulting grief. One woman shared the sense of betrayal and lack of emotional support she experienced when her family failed to acknowledge the significance of her being repeatedly sexually abused by a family member:

I was molested when I was in third grade by someone who lived with us — my uncle. Someone I trusted. Then when my mom and my aunt found out, because it wasn't just me — he was doing it to my cousins across the street from us too. When the adults found out, all they did was ask him to leave the house!

I can still remember waking up, and I would hear him coming. He would be in my room and he would be touching me and stuff. Now I'm a grown woman living on my own. The other day my mom called and said, 'Your uncle's here visiting. You need to come by and see him.' Like nothing ever happened — like it didn't even happen to me. What kind of mother does that to her daughter?!

Unresolved grief can also happen following a loss others might not feel is particularly traumatic, such as a pregnancy loss or miscarriage. He Because an estimated 15-20 percent of pregnancies do not come to term in the United States, the person experiencing the loss might act as though nothing has happened. This is common when there is stigma or shame surrounding the cause or perceived cause of the loss. One woman we interviewed described how she believed her substance use caused the death of her unborn child:

I had a stillbirth caused by my drug use. I wasn't on methadone then — it was street drugs. I was delivering (the baby) naturally and (the nurses) were getting stuff ready. (The baby) was coming feet first because she was very early and dead already for two weeks. It was a horrible experience. I remember asking (the nurse) if I could have something for pain and she said, 'No. You wanted to take your own medicine, so now deal with it!' Everything was happening so quickly; nobody even knew I was pregnant. When they found out I was delivering, everybody was like, 'She was pregnant?!' So (the nurses and doctor) said, 'Look what you did to your baby!'

But, I should have expected that after what I did to an innocent human being? My son's dad was there with me, but they kicked him out because of the way everyone was treating me. He said, 'You don't have to treat her like an animal!' He was cursing at the doctor, so they kicked him out, and then I was all alone in the delivery room in pain and delivering a dead baby.

Environmental Stressors

The women and their significant others discussed how common substance use was in their environments. The availability and access to substances placed them at risk for early initiation, relapse and overdose. From a young age, many women reported growing up in households where family members actively used substances in front of them. Nationally, 8.3 million children under 18 (12 percent) are raised in households where at least one parent has an SUD or is using substances.⁷ For some of the women, seeing family members using substances attracted them to the substances and became the reason they initiated their own use. For others, having experienced the struggles of their family members and still following their path to substance use filled them with significant regret and shame.

Just seeing my family members, seeing the people around me and what they've gone through and what they're going through. It's how they lost everything. I think that kept me away from drugs for a long time — just not wanting that life. But now I'm here too. I can't say nothing bad about my family members because I'm here too now.

I fell into that same trap they did. Even though it wasn't intravenous drug use, I'm still here. I'm still having to take methadone. I still feel like I've failed. I have a couple of cousins I hadn't seen in years who go to my same methadone clinic and are on methadone. I run into them here. 'I'm like, you're here, too?' It's weird. They're heroin addicts, I'm a Vicodin user. Still in the same family. I just never thought I would end up here. I never thought that when I had a baby I'd have to deal with (child welfare). It's an embarrassment to me and an embarrassment to my husband's family — my mother-in-law, my father-in-law. I don't want this for my children.

Often, the women's social circles included friends who were deeply involved in substance use. Several women found it difficult to abstain from use when their friends continued to use.¹³ A woman recalled relapsing after attending a party with her friend, causing her to begin a pattern of selling and using:

I had been clean nine months. I started drinking and my friend was like, 'Hey, I got a couple bags of dope.' I said, 'No, no.' So, he was like, 'Oh, so now you think you're too good. You better than us now, huh?' I said, 'No, I just don't wanna get hooked again.' But then I said, 'Alright, make me a line.' I snorted it. And then the next day somebody was just passing out dope for samples, telling me try this and there I go again. Before you know it, bam, and I'm on the streets selling drugs, using drugs. Then I found myself using more and more and more and sold a whole bunch of it. I started neglecting everything, even my kids.

The physical environment of the women and their families also served as a trigger for relapse, since the physical environment evoked memories of past substance use. One woman described how readily available substances were to her and how her family members had sold them:

My issue is the neighborhood I live in. Right next door they sell dope and everything. My brothers would sell dope and just being around that, and even if I try to stop, just seeing them was tempting me to want to do some too. I thought it was cool because my brothers were doing it and their friends were doing it. I wanted to fit in, so I would do it too.

Many of the women considered moving away to a different neighborhood as a means of getting away from memories that threatened to jeopardize their recovery. They felt that remaining in the same environments placed themselves at risk for relapse and their children at risk for future substance use. A mother of three young children told us:

I wanted to take my children away from where I grew up... where all the bad stuff happens, all the drugs, all the bad people. I took them to a better neighborhood. I want it better for them. Not just for them, but us too — me and my family. I told my mom, I wanted to get out of there. I don't want to stay where the drugs are, where my old friends are. But when you stay in a place where you create a bunch of bad memories, that's what you revert back to. You're used to, 'I bought pills here,' or 'I did this here, I did that,' that's what replays in your mind when you pass by there.

Or, when you go to the store and you're like, 'Oh, I used to always get pills here and I used too, you have to start over and make better memories'.

Unfortunately, many of the women lacked the financial resources to move away and instead described a sense of feeling "trapped" in that environment where previous substance use had happened. Feeling trapped included concerns for their children being exposed to "that way of life" and the potential for their children to follow the same path of multigenerational substance use.

My mother gave me cocaine. My mom smuggled and everything, and she sold... for as long as I could remember. I was 4 years old, and I remember my mom making up baggies and selling. It was normal to be around drugs. That's how I grew up, around people that did drugs, sold them, and gave them to me. I was getting high in sixth grade. I had already smoked rock cocaine.

The women described how their environment created a sense of hopelessness. It was perpetuated by poverty, violence and a lack of opportunity which made their futures and futures of their children seem likely on the same track.

I know a lot of people; they do drugs because they don't have nothing to look forward to in their lives. Like, they're bored. A lot of people, including me, when you're out there, it's like you don't really have nothing to look forward to. You have all these crappy jobs like me, waitressing for \$2 an hour.

While the physical environment was a concern for many of the women, their social environment was equally as important. Many described feelings of isolation and referred to themselves as loners who had difficulty allowing others to get close to them. Most agreed that having supportive people in their lives either was or would be helpful. This is more evident during the postpartum period when many felt alone and overwhelmed.

After you have your baby... I think that's what you do need the most. You need someone to talk to and to motivate you and to help you understand that there's other ways.

The women shared their past stories of childhood trauma, intimate partner violence, loss and unresolved grief. They said these factors contributed to their persistent substance use, relapse and, in several cases, overdose. Any of these factors, alone or coupled with mental illness, left them more vulnerable to turning to alcohol or other substances to help relieve or numb their feelings. Less-than-ideal environments and environmental stressors impeded their efforts to quit substance use. Some of those were:

- Family and friends who didn't support them provided negative influences or hindered their efforts.
- Feeling "trapped" in places that triggered their substance use and did not provide positive environments for their children.
- A feeling of isolation and lack of positive influences.

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Chapter 3



y name is Christine. My son was born withdrawing from heroin, and for that I'll never forgive myself. I hurt him. If it wasn't for my drug use, my own stupidity,

he wouldn't have had to feel that horrible pain of withdrawal. I put him through that. So, I had to be there for him because he was just a baby and he needed my help. I needed him, and he needed me. I needed him because I felt... I did wrong by him and I had to make it right. He was just this little angel...a baby. He didn't know what I was, what I did to him. How could I have done that to him? He couldn't possibly ever understand, so I had to own it and be there for him — to comfort and love him. I put him in that situation, and I, myself, had to be there to help him. No one else could do it, only me; his mother.



or most of the women interviewed, their pregnancies were unplanned and unexpected but not necessarily unwanted.^{7,8} This is not uncommon for women experiencing SUD. About 90 percent of pregnancies in the United

States that happen to women with SUD are unplanned. Because of the unexpected nature of their pregnancies, the women felt they were left with little time to prepare and many didn't know what to expect.

The women we interviewed felt certain their substance use would affect their babies, and many of the women said their babies' health was their main concern throughout their pregnancy. The women told us they wanted to immediately stop using when they discovered they were pregnant, but they feared their withdrawal symptoms would do more harm to their babies than the actual substances they were using. Some of the women feared their substance use would result in their babies being born with physical defects or intellectual disabilities that might later emerge. One woman shared her mixed feelings about this possibility:

Right before I was going to have her I was really, really scared. I was scared for her to come out missing a part of her body or that something would be wrong with her. I didn't want to hear that. I didn't know if I was going to be able to take care of a baby like that.

Opioid Use Disorder During Pregnancy

A pregnant woman diagnosed with moderate to severe opioid use disorder should be offered medication assisted treatment (MAT), which is a combination of medication and counseling, along with other behavioral

health interventions such as recovery support services. Pregnant women with OUD should be advised not to abruptly discontinue opioid use, or to "go cold turkey," because of the risk of maternal withdrawal, relapse, overdose and fetal distress. ^{1, 2, 3, 4} The medications used for MAT in pregnancy, methadone and buprenorphine, prevent the physical withdrawal symptoms that accompany abrupt discontinuation of opioids. ^{12, 13} There is more than 40 years of research showing the safety of methadone use for OUD during pregnancy. Buprenorphine is a newer drug, but it is also considered safe for use in pregnancy and can offer some additional benefits, such as less severe NAS symptoms in prenatally exposed infants.

Pregnant women are often told by family, friends, professionals, Child Protective Services (CPS, often referred to as Child Welfare), probation/parole and medical professionals to stop using opioids or reduce opioid use during pregnancy. Some are even falsely told using MAT is "just replacing one drug for another." The women we spoke with discussed how confusing it was to receive conflicting information and recommendations from multiple sources.

Misinformation was more evident regarding breastfeeding for mothers who were receiving MAT.¹¹ The current guidelines for MAT and breastfeeding state not only is breastfeeding safe but it should be encouraged; this is not a new recommendation. Only small, clinically insignificant amounts of the medications used for MAT pass into breast milk. Breastfeeding has been found to ease some withdrawal symptoms in newborns. Yet, the women we interviewed described receiving contradictory information. On the topic of breastfeeding, one woman recalled:

At the hospital, one of the nurses said, 'Oh, you're on methadone? Don't you think you shouldn't breastfeed? The baby's going to be sick and you're going to be torturing it by giving it more methadone.' I said, 'No, that's not right. That's not what I was told.' So, I didn't listen to her. Then, she also said, 'You were using while you were pregnant? Oh, my God... they should put people in jail for that.' I just thought, you're a nurse. You're not supposed to be saying things like that.

There are numerous benefits for pregnant women with OUD who are stabilized on MAT, including:

- Lower risk for overdose.
- Reduced risk of infectious disease transmission.
- · Better nutrition.
- Fewer pregnancy and birth complications.
- Improved birth outcomes.
- Better coordination of care.

However, the use of MAT during pregnancy can still result in NAS.

Neonatal Abstinence Syndrome

NAS is a collection of withdrawal symptoms observed in infants prenatally exposed to opioids. These symptoms are similar to those experienced by adults going through withdrawal such as: sweating, joint and muscle pain, vomiting, diarrhea and sleeplessness. However, one symptom unique to infants is a high-pitched, inconsolable cry.

Since most of the women we interviewed experienced opioid withdrawal, they described how the thought of their babies experiencing these symptoms was shameful and unbearable for them. They also found their inability to console their infants' cries particularly heartbreaking.

I would see him in his little hospital bed, and he would just be shaking and crying. It didn't seem to matter what I did. I couldn't make him feel better. Most of the time I would just hold him and cry too. How could I have caused him so much pain?

Many women described their disappointment in themselves for having continued to use substances while pregnant. Regardless of other past regrets, they explained how their continued use of substances was one that would likely persist for a lifetime. This regret was felt so intense by some of the women it caused physical symptoms of pain and disgust that evolved over time into deeper, longer-lasting feelings of shame.

Years from now, no matter what mistakes I've made — divorces, marriages, whatever — the one mistake, the one thing I will always regret, is using while I was pregnant. That is just the lowest thing to me. I think back on how I looked down at my pregnant belly and still stuck a needle in my arm. Oh God, I just get sick to my stomach thinking about it still today.

For many of the mothers, one of the hardest and most dreaded experiences they anticipated was the day they would have to tell their child about their SUD and having used while pregnant.

One woman described how she thought that conversation with her children might go:

I will always be honest with my kids. I don't want to lie to them, but I am so afraid of their reaction when I finally do tell them (about my drug use). Oh, my God... I'm so scared that they're gonna hate me. I just don't want them to hate me. I guess I'll start out with, 'I love you so much and where that love came from, it's like nothing I've ever felt for anybody in my entire life. You were born, and it was just there. I didn't even know who you were. I don't have any idea what kind of person you'll become. It's not even that I created you or that you're a part of me. It's just there. The love is just there.' Yeah, I'll probably start out with that.

NAS Care

While there isn't a universally-approved treatment protocol for infants with NAS, infant care is typically provided in a neonatal intensive care unit (NICU) where infants might experience a long hospital stay. 5, 6 Symptom management usually begins with common soothing techniques that can be effective with any fussy baby: swaddling, rocking, skin-to-skin holding and breastfeeding. Medication is typically only used when sooting techniques are ineffective in controlling withdrawal symptoms. 10 It is important to note infants born experiencing the withdrawal symptoms that follow physical dependence to opioids do not meet the criteria for a diagnosis of "addiction" or OUD.

Therefore, infants should never be referred to as addicts or be considered born addicted or in need of rehabilitation.

Because of the nature of most NICUs, babies are often separated from their mothers leaving nurses to serve as their primary caregivers. Considering most nurses are assigned several patients, it might be difficult to implement time-consuming, soothing techniques. Mothers told us the NICU environment made it difficult for them to implement soothing techniques, and they often found themselves confused about their role in their baby's care. They reported feeling uncomfortable visiting the NICU, and incapable of comforting their babies. Numerous barriers to spending time with their infants were identified. For many, it was difficult to be present because experiencing their baby's withdrawal symptoms was unbearable. The sense of guilt for having caused this discomfort was often overwhelming.

When I'm going through withdrawal, it hurts me. Knowing that (my son) was going through withdrawal because of what I did...he was the one having to go through it now. Hearing that he can't stand what hurts him, can't tell me what's bothering him, or how he feels, or what I should do to make him feel better. It just hurt me. I would cry. You know, he was just an innocent little baby. He didn't know what I was doing. It really hurts me.

In some cases, the guilt associated with seeing their babies' withdrawal symptoms exacerbated the women's OUD and contributed to a return to, or an increase in, use.

I had a lot of guilt, so that drove me even deeper into my addiction. Of course, I didn't want to feel that pain when I went to the hospital to see my daughter every day while she was in the NICU. So, I used more and more and more to mask what I was feeling because of what I did. It just became a vicious cycle of never-ending use.

One significant barrier to visitation often reported by mothers was the bias and stigma they faced during their encounters with health care providers. The women described their feelings of being unwelcome in the NICU. They shared unkind and hurtful comments made by health care providers they heard directly and indirectly during their visits. These comments were particularly harmful and resulted in intensified feelings of guilt and shame. One mother relived an event that had happened during her infant's NICU stay:

I heard one nurse tell another nurse this about me, 'She's a methadone patient. You should never leave her alone with her baby by herself.' It made me feel terrible — like I was going to hurt my baby! There were a lot of times when the nurses would make little comments like that. It made me feel different than the other moms who weren't on methadone. (The nurses) would say, 'You're a methadone mom and we suggest that you be accompanied by somebody at all times because we don't know what might happen.' It really hurt me. They watched me all the time and would be like, 'Don't touch (your baby)! Don't wake him up because we had a really hard time getting him to sleep.' And I'd be like, 'OK. You know, that's fine.'

They always had something to say when I was going to change or feed him even though I always asked them, 'Does he need to be fed?' And they'd be like, 'Yes, but let him sleep some more because it wasn't easy getting him to go down.'

Several of the women reported calling the NICU before planning a visit with their infant. If the mother had experienced a negative encounter with a certain nurse in the past and she was on duty, the mother would stay home instead.

I heard one nurse say to the other, 'You're going to have a lot of problems with that little baby because he's real jumpy and jittery. His muscles are locking up because of his junkie mom.' After I overheard her say that, I didn't want to visit anymore. I would call before coming to see if (that nurse) was there. If she was, I wouldn't even go visit my baby. I just couldn't take it. I didn't want to be around that nurse because she just made me feel so uncomfortable.

These types of interactions were damaging toward the recovery for some of the women.

You're not a very strong person when you're in your addiction. So (feeling unwelcome in the nursery) can be a trigger and it's easy to just be like, 'You know what? Whatever! They don't want me to see my son? Then I'm not gonna see my son. I'm gonna keep using and leave him there, and never go back.' You're feeling so guilty, so low, that you just completely go off the deep end because those feelings are powerful, and they can completely ruin a person.

Although the women might not have felt strong enough during their infants' hospitalization to advocate for themselves, many thought they were treated unprofessionally and unfairly. This type of treatment was also not what they expected from a hospital where people, with many different needs, go for help.

I didn't expect to be treated that way in a hospital. I really didn't because it's a hospital! People pass through there for all kinds of reasons; a lot of things. But, I guess it's totally different when you're the mother of a baby born withdrawing. I wish I could tell the hospital that when a methadone baby comes to them, not to think the mother doesn't care or that she's just gonna end up losing her baby anyway.

While some women did share negative encounters during their infants' hospitalization, others recalled positive interactions with health care providers. They explained how these supportive encounters made them feel like a person and helped them with their already fragile self-esteem.

One day in the nursery when I was visiting my son, one of the nurses said to me, 'I don't know what you've been through, girl, so I'm certainly not gonna sit here and judge you. All I know is that you're here now for your son, you're taking good care of him, and you're a good mom.' That just did so much for my confidence. You have no idea. And, it really helped me to connect with that nurse and to trust her. I just can't say how much that meant to me to hear those kind words from her.

Several of the woman provided insight they wanted to share with the nurses who cared for their infants. They felt these suggestions could make life a bit easier for women like themselves in the future.

(The nurses) would be rolling their eyes. I don't think they tried to do it intentionally for me to see but I did see it. It made me feel so ugly... like, 'What did I do to you?' I mean, if they were really to get to know me, I think they wouldn't do things like that. I'm a really good person, not just a heroin addict! I felt like it was really mean. Plus, I wish (the nurses) would just do their jobs and let others do theirs. I mean, social workers are supposed to talk to us while (our babies are in the hospital). They're supposed to ask us what our plans are after we take our babies home and all of that — not the nurses! The nurses just need to take care of our babies during their shift, then the next shift comes in, and they go home.

Another woman offered this advice:

I would just tell (the nurses) to take it easy (on the mother). You know, after being addicted, I realized that this is really a disease. There are some who abuse (drugs), but if you're using while you're pregnant, you have a problem; a serious problem... and you need help. You obviously don't care about yourself, about anything, except the drug. Make it a little bit easier on that mother if she's showing initiative... if she's taking the time to be there. If she loves her child, you can see it and you can feel it. If it's obvious that she's there for the baby, then embrace her; make it easier. You don't know what her circumstances are.

You don't know what she's been through or how hard her life has been. You don't know what she was feeling when she was pregnant... if she was being abused, if she was poor. Whatever the reason she was using while she was pregnant... you just don't know. So, try to make it easier for her.

Long-Term Outcomes in Children

Most of the mothers shared their concerns over developmental delays and behavioral issues they feared their children might develop in the future because of prenatal opioid exposure. One mother said:

I worry about my son developing learning disabilities. I heard that he can from methadone exposure. His pediatrician even said he's at greater risk for developing (attention deficit hyperactivity disorder) and other behavioral problems because I used during pregnancy. So that's my biggest concern.

There's no scientific evidence connecting prenatal opioid exposure with poor developmental or behavioral outcomes in children. While some research determined a relationship might exist, the current science fails to support developmental delays, behavioral issues and poor long-term outcomes for infants who were prenatally exposed to opioids. However, treatment of the mother is likely to lead to more positive outcomes for the infant as they grow.

Many of the people we interviewed faced multiple challenges in addition to SUDs including: poverty, food and housing insecurity, and under/unemployment.

These challenges, often referred to as social determinants of health, are known to impact lifelong health and early childhood development, making it more difficult to show a direct cause-and-effect relationship between developmental outcomes and prenatal substance exposure.

Child Welfare

The women shared their insight about their struggles with child welfare, including the trauma and embarrassment their involvement caused for them, their children and the rest of their families. They explained how child welfare involvement had "complicated their lives," "separated families" and "filled parents with fear and terror." The mothers described having their children removed from their homes and losing custody. One family member explained the despair her sister experienced following the removal of her children and how she believed this contributed to her sister's overdose death:

She finally gave up. She didn't want nothing to do with life anymore; her children were gone, and I think she (overdosed) on purpose. (The rest of our family) doesn't believe she was trying to kill herself, but I do.

National trends of child removals support the mother's fear. From 2012-2016, there was a 10 percent increase in children entering the foster care system after more than a decade of steady decline. In the six states most affected by the opioid epidemic, there was a 50 percent increase over this same four-year period. Of the 268,212

children under 18 removed from their families in fiscal year 2017, 96,400 (36 percent) had parental drug abuse listed as the reason for their removal.¹⁴

Many of the mothers shared the hopelessness and despair that accompanied child welfare involvement and the removal of their children. Some felt this could be a motivator for women to get the treatment they needed, but more commonly the women described this as a "crushing blow." Several knew women who had relapsed into substance use and had experienced fatal overdoses following child removal.

Some women who lose their kids to CPS (Child Protective Services) are more motivated to get help and reunite their family, but others get so discouraged that they relapse because they are at their lowest and feel like they have nothing left and they're powerless. They get depressed and they lose their motivation. They feel like they have nothing to look forward to in their life. They feel hopeless, you know? Since they don't have their kids to look at when they wake up, they have nothing to look forward to. There are no kids. What do they have to wake up for? What do they have to start their day for? They don't have anything anymore.

While several of the women had caseworkers who were helpful and supportive, many others did not. The message made clear by the women and their families was it "all depends on which caseworker you get." Among women who lived in the same communities, it was well known certain caseworkers intentionally "make life difficult for you." Several women who were receiving prescribed

MAT as recommended described how a child welfare case was still initiated at delivery and caused continuing difficulty in their lives:

When you have a methadone baby, you also end up with a CPS case no matter what you do. Even though methadone's prescribed and legal, it's not seen that way by CPS. I guess some people just think the mom's not gonna do what she needs to do to keep her baby. Or, they're thinking she's at the hospital because she has to be there not because she wants to be. They also think when the baby goes home, the mom probably won't be there at all or will just give the baby to her family and that's it. So, CPS goes and gets involved.

One man described how he believed child welfare removal of his daughter led to his partner's eventual overdose death:

I think (the events that led up to her death) began when (child welfare) got involved... you know, the day she went into the hospital. I don't think she wanted to tell them about the drug use, but they found out. They said, 'We know you use heroin. We've got to have (child welfare) involved.' And the next day they came in and talked to both of us about temporary custody. When they came in with the news, she started crying a lot. When they said, 'We gotta take the baby away,' she knew it was gonna happen. But still... she wasn't ready.

The women also described the invasive nature of having strangers intimately involved in their families' lives.

One woman recalled an event at her home when she received an unannounced visit from her CPS caseworker at midnight:

My family was all sleeping when there was a knock at our front door that woke everyone up. My teenage son was so embarrassed, and my little ones were terrified they were going to be taken away. It took me hours to calm them back to sleep after the caseworker left.

She further discussed the impact her SUD and CPS involvement had on her teenage son and shared details about a visit her caseworker made to his school:

Yes, it's very hard to know (my son) worries about me, and that he knows things in his head. He has things buried in there that he doesn't want to tell anybody. He won't tell a soul. He'd never tell anyone that, 'My mom is on methadone. My mom goes to the clinic.' Just having CPS involved in your 16-year-old's life – how does that make you feel? A CPS guy goes to his school, pulls him out of class, and talks to him – in high school! You don't want people you're not familiar with in your personal life. You don't want people looking at or talking to your children or going to their school. That's like a – that's embarrassing! It's just embarrassing!

As CPS intervention increased, mothers got more access to community resources, referrals and community education programs. Most mothers discussed the associated stress and its negative impact on their lives and early recovery.

Stress

Several women described how the multiple, complex and competing demands placed on them following childbirth also jeopardized their recovery. Many of the mothers were alone and the sole source of income for their families. Most had open child welfare cases or were on probation. Their lives consisted of numerous, mandatory classes each week in addition to daily methadone dosing, relapse prevention, parenting self-help group meetings and probation requirements. One woman described her schedule and how she felt she was being "set up for failure":

I was on probation and I had CPS on me. I was doing counseling and parenting classes and still being a mom and a wife, everything just got to me. I cracked underneath all that pressure they put on me. You know, I had a lot of bills to pay. I had to pay for drug tests I had to take. I had so many classes, (Narcotics Anonymous) meetings three times a week, three different counselors. I had to take a bunch of parenting classes. It's just like amazing the things they overwhelm you with. For a minute I was like, man, I should have just stayed in jail.

Summary

The opioid crisis has affected mothers and their children in Texas. The mothers we spoke with discussed lack of contact with their child, whether through the NICU setting or out-of-home placement, as a significant barrier to their recovery.

Chapter 3

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Chapter 4



y name's Cassandra but my friends call me Cass. My children are everything to me. Without them, I'm sure I'd still be living on the streets, or maybe even dead

by now. That kind of life isn't even an option for me anymore. I have to be here for them. They make me want to be a better person. I look forward to waking up each morning to see their little faces and I can't wait for them to get home from school in the afternoon. I never would have thought my life could be like this – normal. I wish their dad could see us now. He was my best friend for 10 years. But, I had to leave him because he was still using. Hopefully, one day, he'll see me and our kids doing so great and wanna come along, and then he can be in our lives again. But, I know he's suffering, and I know how that feels. If only he could know that it feels this good to actually be sober and be OK with yourself. It's a lot of work, though. It's a lot of hard work.

The Role of Motherhood



he mothers we interviewed shared how their motherhood experience changed them, and their children were a vital role in their recovery. Although most of their pregnancies had been unplanned, and

several first discovered they were pregnant while incarcerated, most felt their pregnancy had purpose and meaning. In some cases, this meaning was discovered during their pregnancy, but for others it happened after their babies were born. A mother explained how she believed her daughter was a divine intervention in her life, "I think God sent my daughter to me, so I would snap out of this life I was living." Another mother said:

I think things happen for a reason – everything. Maybe I wasn't being the parent I should have been. If I wouldn't have gone through all I've gone through, I don't think I would be who I am today. I wouldn't be as strong. Everyone has problems. I have problems, but I handle them differently now that I'm in recovery and I have children to raise. Before, I would use an argument or some other stress as an excuse to go use. All I've been through has made me see that you're gonna have ups and downs. You just have to handle them a different way. I'm a much better mother because of all I've been through. I really don't know what exactly led to me using in the first place, but I am so much stronger today than I was back then. It's all because of what I've been through.

Mothers also explained how they felt pregnancy and motherhood provided them with an opportunity to redeem themselves. Some were fortunate enough to regain custody of children who were previously in the care of family members, oftentimes grandparents. However, the mothers also described how this opportunity carried with it more responsibility and a desire to live up to the challenge.

I myself have not been the most perfect parent at all, but with this child, I can redeem myself. With my kids coming back into my life I can redeem myself. I want to show them that just because their mom, for the majority of their lives, saw things her way – living in a world of her own with drugs and violence, it's not all about that. Underneath all of that was a person inside who really needed help, and who's willing to go through whatever it takes to be the person she's supposed to be.

While not much evidence exists to show the impact children can have on recovery, based on our interviews, children seem to be an important and positive role in many mothers' recovery. Research shows women who remain with their children while accessing treatment services, rather than being separated, are more likely to successfully complete treatment and enter long-term recovery. Motherhood can be viewed as a shared, lived experience, and source of support among parenting women. For example, a mother living in a recovery home for women and children explained how much it meant for her to live with other parenting women:

We're all dealing with the same problems. So, they don't judge me, and I don't judge them.

Other mothers described how a somewhat natural and informal mentorship begins to emerge when parenting women live together in recovery.

The newer women can sort of look up to the women who are further along and feel like, 'You know what? She did it. I think I can do it too. And, that really helps.'

The mothers who were early in recovery also shared how they would ask the more experienced women for advice and support. As women progressed, they also enjoyed becoming sources of support for newer residents. One woman described her experience in the recovery residence this way:

I love being here with all of these women who are dealing with the same issues as me. We don't judge each other. We help each other, and we take care of the children together... and the children are really happy and content. I've never had this before. It's great there are women here who are further along in their recovery than me and I can go to them when I have a question or when I just need to talk. Now that I've been here a while, there are also women who are newer in recovery than me. It's nice that I can help them and let them know that anything's possible. This place has been a blessing for me and my children.

The mothers talked about how the routine necessary to raise healthy children forced them to rethink the way they were living.

Many spent time homeless, which is incompatible with mothering children. Realizing this helped them decide it was time for a change.

The whole thing about (my son), I can't have him out in the streets at all hours of the day or night. I've got to think about him now. It's not just me anymore. It's not just about me anymore. I've got to think about him and my oldest child too, you know?

Looking to the Future

The mothers discussed their hopes and dreams for the future. While these included a desire for their children's happiness and a better life, a continued, underlying theme of regret for past actions seemed to be in their plans.

I am a drug addict. I am a horrible mom, but I am still a mom. I am still having to be responsible for (my children). I've already done enough damage. I'm determined to fix this. I don't need them suffering any more than what I've already put them through. I have to take care of them. It's not their fault. It's not my daughter's fault. It's not (my son's) fault that I'm the way I am. I still have to take care of them, and I'm going to despite it being late. It's better that it's late than never.

The mothers shared concerns that as their children grow up, they could end up following the same path into substance use. They described the possibility of this happening to their children as unacceptable and many of the women felt that if their children did, it would be their fault.

I don't want my kids to ever have to go through the suffering I have. You know, all the using, being homeless, being in jail, losing their – losing their kids or anything like that. I don't ever want them to feel any of that hurt. And, I feel like if my kids do suffer, it will be all my fault because I didn't give them a fair chance.

Several mothers discussed how they ensured their children had a different life than they had. This included going to great efforts to serve as a role model for their children. Mothers wanted their children to see them maintaining their sobriety and providing a good life for them. A positive maternal role model was something many of the mothers we interviewed had not experienced, which made it even more important for them to be that role model for their children.

I want to be a good example for my children. I want to show them yeah, your mom went through a difficult time, and had a rocky life. I put myself there, so I had to suffer the consequences. But, I don't want them to think that it's OK to go and find drugs just because you had a setback. I want to show them to keep moving forward and continue going to church and making something of themselves. Otherwise, I'm afraid they're going to think of me as not trying. I really don't want them to have problems with drugs, but I'm afraid they will.

Giving Back

The mothers were also committed to "giving back" and helping others who had been in their "same situation."

They were grateful for the opportunities they had been given to change their lives and parent their own children. They also had empathy for women still struggling to achieve recovery since they also faced the same struggle. Some even struggled numerous times before achieving sustained recovery. As a result, the women we interviewed felt even more determined to tell women recovery was not only achievable but "wonderful." Many were surprised by how great their lives had become, and they wanted to share with others.

My life is wonderful now. I have a full-time job. I finished school. I have my daughter 24/7. I only have to be away from her when I'm at work, but even then I miss her so much. Life is amazing. There's so much to life and so much to enjoy. Life is so beautiful! You only get to do it once so why not do it the right way.

Like their desire to give advice to health care providers who might not fully understand the disease of addiction, they also wanted to advise women who might be considering treatment and recovery services but who are afraid. They wanted women to know it was alright to reach out for help.

Advice I would like to give to any woman who finds herself in my same situation would be to get help as soon as you can. Don't be afraid. Don't be ashamed. The sooner you can get help, the better. Things will get better... they really will get better for you. It might feel like the end of the world, but it's not.

The mothers wanted others to understand the love and bond between a mother and child could be transformative beyond their imagination; so much so it had the power to change their lives.

After my daughter was born, I would place her skinto-skin on my chest and just look at her for hours. I would think, look at how beautiful my daughter is. No drug... nothing can make me feel this love she's making me feel. Somebody needs me. Somebody cares about me. I don't even know this person and she already loves me and needs me. Nothing can ever replace the love that she gives me and the way she makes me feel.

The bond these mothers had with their children was so strong they were willing to fight their SUD for the rest of their lives if necessary to keep their children with them.

Keeping my children is my reason for staying clean. I'm willing to fight my addiction for the rest of my life if that's what it takes to be a mother to my children.

Summary

The stories shared by these mothers illustrate how recovery is achievable, and that motherhood and children are an important role in the recovery process. While some of the women might wrestle with regret for the rest of their lives, they are hopeful for a future that includes mothering their own children. The empathy and support they have for one another is inspiring, as is their desire to give back to society. Future models of care and service delivery that protect the important, yet delicate, mother-child bond is essential.

These models must be gender-specific and womancentered if they are to protect families and contribute to healthier communities and future generations.

Chapter 4

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A Message From the Author

My name is Dr. Lisa Cleveland, and I wrote this book. The women who've shared their lives with me over the past eight years have changed me forever. I once said my first encounter with a woman who used heroin happened by 'chance,' but I don't believe in chance anymore. I feel certain I was destined to meet Ruby. We met when I was conducting interviews for my dissertation study, which was focused on a somewhat different topic. Ruby asked me to come and interview her. She wanted me to hear her story, so I went. She opened my eyes to a vast world of suffering and pain, but she also showed me a world filled with incredible compassion, beauty, strength and hope. Thank you, Ruby. You've made me fearless beyond my imagination and you've taught me to say 'yes' when called upon to serve others. I am eternally grateful to you for showing me my purpose in this life.

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